Health Innovation East Midlands
Local change, national impact

Joined Up Care Derbyshire

Learning from the Joined Up Care Derbyshire Chronic Pain Support Groups

Kate Hardiman
Rich McBain
Lisa Towle

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Contents

Introduction *2*

Background *2*

Review of the Let's Live Well With Pain (LLWWP) groups *4*

Method **4**

Findings from the review **5**

Observation of the sessions 5

Focus group feedback 6

Feedback from group facilitators 11

Discussion *13*

References *16*

Appendices *17*

Appendix 1: JUCD system approach to improve the management of chronic non-cancer pain **17**

Appendix 2: Why opioids are not the answer for chronic non-cancer pain **18**

Appendix 3: Pain Management Support Group Visits - Questions **19**

Appendix 4: Pain Management Support Group Visits – Consent Form **21**

HIEM and JUCD would like to say thank you to every single group participant and the group facilitators for allowing us to observe, giving their time, and sharing their experiences.

Introduction

At the time of writing, Joined Up Care Derbyshire (JUCD) has 21 chronic pain support groups based on the 'Lets Live Well With Pain Programme' that has been developed locally, grounded in the ten footsteps approach to Living Well With Pain. The groups are all based in the community rather than in hospital and have all been adapted to suit their local area needs. The aim of this review is to understand what works well for these groups, what can be improved, and to understand what the participants feel about the support they provide. We hope that the findings will support shared learning and further adoption of the pain support programme to other areas in JUCD.

This work is part of a broader piece of work within JUCD that is being supported by Health Innovation East Midlands (HIEM) that aims to improve the management of chronic non-cancer pain (CNCP) and reduce harm from opioids (see Appendix 1 for more information).

Background

Ongoing CNCP is often termed 'persistent pain' and usually described as pain that lasts more than three months that is not related to a cancer diagnosis. Unlike acute pain, CNCP is not related to tissue damage, but people experience persistent pain that can be severe and negatively affect their daily activities and overall quality of life. Pain medicines such as opioids are not very effective at reducing CNCP but can cause sever side-effects that can reduce quality of life and can cause death. For more information on why opioids are not the answer see Appendix 2.

'Live Well With Pain' (LWWP) is a not-for-profit organisation that is run by an alliance of healthcare professionals working in pain management, and people with lived experience of persistent pain. They share a passionate belief in the power of self-management to improve the lives of people living with pain. By combining their professional and personal experience they have developed a range of self-management resources that have been tried and tested including the 'ten footsteps to living well with pain'. The steps are easily explained and allow people to understand why they are feeling the way they are, which is known to be vital to coping with chronic pain. Steps include acceptance, pacing, communication and managing moods, and can be delivered via a manner of methods.

Through the wider piece of work within the JUCD, HIEM identified the ***Let's Live Well With Pain Support Group*** based at Lister House Medical Centre as an exemplar example of providing local pain support. The six-week pain support programme had been developed by local health and wellbeing coaches with the support of LWWP and was based on the ten footsteps approach. HIEM supported the sharing of the approach across JUCD and worked with LWWP to develop resources to support the development of further programmes both locally and nationally including a facilitators guide and implementation guide.

The 'Let's Live Well With Pain Programme', which recognises self-management as key to living well with pain and improving quality of life, can be adapted to suit local needs and capacity. This approach advises a six-week pain support programme following the ten footstep approach to develop acceptance and learn how best to manage CNCP.

This approach has been designed to help patients:

- Learn effective skills and methods that support the self-management of their pain, allowing them to live better despite experiencing ongoing pain.
- Increase their confidence and knowledge to take control of their own pain management and improve overall wellbeing.
- Learn from, and share experiences with, others who are living with ongoing pain.
- Consider how well their pain medication is working for them and access support to review their medication.

More information about the Let's Live Well With Pain Programme can be found here.

HIEM supported JUCD by providing funding to increase the number of healthcare staff trained as LWWP practitioners in the 'ten footsteps approach'. At the time of writing there are 60 trained staff with 20 more in training across Derbyshire including Physiotherapists, Mental Health Liaison Practitioners, Social Prescribers and Clinical Nurse Specialists, with more completing training shortly. This has allowed the initiation of 20 further Pain Support Groups bringing the total, as of December 2024, to 21 actively running Pain Support Groups spread across eight Primary Care Networks (PCNs) (see Figure 1). Each group has adapted to suit the needs of the local population.

Figure 1: map of the pain support groups available in JUCD

Review of the Let's Live Well With Pain (LLWWP) groups

Method

The review took an appreciative inquiry approach to understanding the groups, focusing on what worked well and how the groups planned to improve, but also captured the learnings from the groups and why variation was needed to meet their local needs. Crucial to the review was understanding how the attendees felt about the groups and the impact it has had on them.

Between October and December 2024, colleagues from HIEM and JUCD attended seven groups. They observed the pain group meetings and, after the group had finished, carried out semi-structured focus groups with some participants and facilitators. Consent forms were signed by participants to confirm that they were happy for their quotes to be used as part of this report (Appendix 4). There were some groups that wanted to take part, but for various reasons could not. With these, the same semi-structured questions were undertaken via telephone with either group facilitators or participants.

For the in-person focus groups, a light lunch was supplied for attendees. No other payment was provided. Those people who volunteered to be interviewed had been previously informed by group facilitators of our attendance, were aware that it was voluntary, and that they could engage as much or as little as they liked.

The HIEM medicines safety improvement delivery team developed the questions for a semi-structured interview, that included input from a pharmacist, physiotherapist and person with lived experience. The same questions were used across all groups and individual discussions (see Appendix 3).

The groups visited were spread across Derbyshire (see Table 1) and covered a range of formats.

Table 1: Pain support groups visited

Group Name	Formal/Drop in	Group facilitator's job title	No. of attendees at group (female:male)	In-person or online	Time of session
Lister House	Formal 6-week course	Health & Wellbeing coach	12 (10:2)	In-person	10:30-12:00
South Dales PCN	Formal 6–8-week course	Social Prescriber(s)	6 (4:2)	In-person	10:00 – 12:00
Derby City South PCN	Formal 8-week course	Physical Activity and Health Officer(s)	7 (7:0)	In-person	10:00 – 12:00
Erewash PCN (1)	Formal 6-week course	GP link worker	6 (6:0)	In-person	13:00 – 14:30
Erewash PCN (2)	Drop in (Pain Café)	GP link worker	7 (6:1)	In-person	11:00 – 12:00
NE Derbyshire PCN	Formal 6-week course	Health Psychologist / Physiotherapist	8 (8:0)	Online	13:30 – 16:00
Chesterfield & Dronfield PCN	Drop in	Social Prescriber(s) / Lived Experience	15 (13:2)	In-person	10:30 – 12:00

Findings from the review

Observation of the sessions

HIEM and JUCD attended 7 pain support group. All the in-person groups were:

- delivered in English
- delivered in community venues such as church halls, social centres etc,
- were accessible to wheelchair users
- were held on the ground floor to increase accessibility,
- had appropriate toileting facilities
- had enough room to allow for activities and moving around.

All groups provided tea and coffee on arrival, and they all also had tea breaks during the session to ensure that people could move around to ease any discomfort as required. These breaks were also an opportunity for the participants to have a chat with fellow attendees and build relationships. The groups were mainly attended by women (58 out of 65) and all were English speakers.

The sessions began with an introduction to the topic of the day, as well as introductions to new starters in the drop-in group. It was made clear that participants could engage as much or as little as they wanted, and there would be no pressure to be vocal if they did not want to be. Five of the seven groups had two facilitators, with one group having only one due to planned absence and the other having three. Having at least two facilitators allowed multiple

conversations to be had, including more private ones if required, during the in-person groups.

Discussion was encouraged by the facilitators throughout all sessions, even if it meant straying from the intended topic. From our observation, it was clear that this was the intended outcome, as it enabled the participants to express their thoughts and feelings and maximise the benefits from the group. There was constant conversation at all groups which demonstrated the comfortable environment that had been created for participants to confidently share their concerns and vulnerabilities.

Each session was supported by LWWP ten footsteps activities/slides that were navigated by the facilitators: some to be completed in session and others to continue in their own time. From observation, there was an informal feel to the sessions with free-flowing conversation and minimal rigidity. At most groups, participants were provided with the 'Ten Footsteps little black book' from LWWP to refer to and make notes in as required.

As we attended a snapshot of each course, there was opportunity to observe a variety of activities including mindfulness, a walk around an allotment, advice in pacing and the importance of communication. These sessions were delivered at a pace that suited all participants, especially the allotment walk, and included advice on how to replicate the activity at home. The facilitators explained that before the physical activity sessions, they discuss the activity and amend the session where required to suit all needs. This ensures maximum engagement, a personalised approach to activities to enable all participants to achieve a goal within session. We observed that was no pressure to engage or continue with the activity, for example, the two men we saw try mindfulness both said it did not work for them; this was accepted and the session moved on.

As well as the more formal support groups we also visited a pain café. The session did not feature an activity as the structure intended to provide an opportunity to catch up with other participants and share thoughts, feelings and experiences. The relaxed nature of the session, along with the location of a busy café, allowed the group to have a more dynamic approach. Subjects of conversation were derived from how people had been getting on, what challenges they had experienced since the last meet up, and what was working for them. This was a lovely session for us to observe, as it allowed us to chat with the participants in an informal manner and gauge an understanding of the benefits of having this support potentially as a wraparound to a 'course' environment.

Focus group feedback

We conducted semi-structured interviews with over 50 participants across the 7 groups after their session either in-person or via telephone call. This was a great opportunity to collect participants thoughts about how the group worked, what they had learnt and how the groups could be improved. All participants were asked the same set of questions (see Appendix 3).

Table 2: Focus group details

Group Name	No. of attendees at group (Female:Male)	Focus group attendee numbers	Focus group or individual discussion
Lister House	12 (10:2)	12	In-person
South Dales PCN	6 (4:2)	6	In-person
Derby City South PCN	7 (7:0)	7	In-person
Erewash PCN (1)	6 (6:0)	5	In-person
Erewash PCN (2)	7 (6:1)	5	In-person
Erewash PCN (3) – evening class	5 (4:1)	Telephone call to group member	Telephone
NE Derbyshire PCN (1)	7 (7:0)	0 (but both facilitators interviewed)	Online
NE Derbyshire PCN (2)	8 (8:0)	0 (but both facilitators interviewed)	Online
Chesterfield & Dronfield PCN	15 (13:2)	15	In-person

The first question addressed the reason for signing up to the pain support groups.

***Question*: What was it about this course that made you sign up and attend today? (how did you hear about it?) what did you hope to get out of it?**

The majority stated that their GP had signposted them to a social prescriber, who had in turn recommended them to the support groups. There were some comments demonstrating scepticism around attending a group but all those with these opinions soon changed their outlook after a session or two. It was reported that this was when they realised that they were likely to take away something positive. Others responded by airing their frustration saying it felt that the referral was more of a 'tick box' exercise and that they 'had no choice' to attend. Having said this, those respondents did say that they found the group useful and had learnt how to manage their pain better.

The format, timing and location of the support groups was then explored .

***Question:* What is it about the format, timing or location of this group that particularly works for you or that you would change or improve?**

With most daytime groups starting mid-morning, the majority of participants were happy, as it allowed them time to get 'moving' beforehand, but they could still have the rest of the day for other things, such as school drop-off and pickups. The only timing concern that was raised was by a participant who was still in full-time employment. Despite his manager being helpful and supportive, he often had to make the time back for attending the course which does raise concern regarding the accessibility of the groups to those who are of working age. There were no concerns voiced regarding location, even from those that had to travel from further away than most, as all locations were on bus routes. For those that drove, car parking did not appear to be an issue, with most sites having plenty close by, so people did not have far to walk from their car.

The structure and format of the groups varied, but from observation and feedback, all groups worked for the participants. By using the 'Ten Footsteps' as the foundation and allowing the attendees to try all activities at their own pace, the participants voiced that they never felt

under pressure to complete everything but that they felt supported to develop coping strategies. One participant who had completed the more formal pain management course at the Royal Derby Hospital (RDH) told us that this informality and interactivity of the sessions meant she learnt more about managing her pain.

The following quotes support the above:

"Loved it and the best part was it being informal and laid back. This approach really got me engaged."

"The sessions were really interactive and were varied in nature."

We then explored the skills that they had learnt to enable improved pain management.

Question: Now you have attended this group, what skills have you learnt or what would you like to learn to help you with your pain?

The most adopted skills were pacing and goal setting, with participants reporting that learning how to pace has enabled them to avoid the peaks and troughs with their pain that had previously been problematic. Goal setting, and breaking down goals into manageable chunks, was also reported to help participants achieve more success when undertaking activities or tasks, especially around the house. The activities we saw linked to this included mindfulness, with one participant stating:

"Breathing techniques have been very helpful. Learning this has helped me to relax."

The next topic involved exploring how attending the groups made the participants feel.

Question: How has attending this group made you feel?

At all focus groups, including the ones via telephone, participants reported feeling much better about themselves and more positive about their pain. As well as the verbal feedback obtained regarding this, it was also clear on observation from the warmth and compassion in their words/voices when they spoke. It was palpable that the sense of "not being the only one in my circumstance" provided wellbeing, and this in turn gave them the confidence to speak up for themselves. The lift in confidence enabled improved communication between them and their loved ones, especially following on from the communication focussed sessions with one participant saying:

"(The) group has helped me be more open with my wife and to understand how she feels."

The impact that the boost in confidence had also allowed attendees to try more activities with the effects carrying over into their personal lives and improving social activities. One lady said:

"My husband has noticed a difference; I'm much more confident and can go out through the door.

The importance of peer support was highlighted in the feedback from the next question.

Question: How important is peer support for this group?

This question prompted the most vocal response in all the groups. The feedback was overwhelmingly positive with participants expressing that peer support was invaluable to each attendee's pain journey. Throughout our discussions and observation, watching how they supported each other, shared coping strategies, listened intently and expressed gratitude for sharing was admirable. Participants became visually emotional when discussing the support and validation they had received from others and expressed how important this was to them:

"I'm not sure I'd still be alive if it wasn't for this group. I didn't previously go out and struggled with mental health, but this group made me realise I am worthy – it saved me. The group of people showed me I'm not alone and have no judgement towards me."

This quote's implication was reflected by almost all people we spoke with. No negative comments were documented regarding peer support and all said that they had taken benefit, comfort or joy from at least one other member of their support group. This is one of the main themes that evolved from our analysis of the focus groups.

Additionally, there were some groups that included people with lived experience as either a group leader or attendee. This was seen to have a positive impact on the success of the groups due to the element of peer learning and support. From our observation, it was empowering and inspiring to the participants attending the groups as it was a clear example that there are ways of living well with pain.

Changes to lifestyle following on from the support groups was then explored.

<u>Question:</u> What changes have you made or have happened to your life/lifestyle because of the group?

The answers to this were very similar to that of the question around how the groups made them feel. As they expressed that their increase in confidence and ability to manage more activities, it led to them being more open to new ideas, being able to say yes/no to things dependant on their own wishes and being able to be more physically active.

One participant stated that:

"I'm more confident now… I don't stop talking. The group has given me confidence to try other things such as chair-based exercise groups."

We felt it important to explore the reduction in opioid medication as part of lifestyle changes. Although not the main aim of the Pain Support groups, all focus groups had some attendees expressing their desire to reduce or cease taking opioid medication for their pain. There is evidence to suggest that for every 62 patients that stop using Opioids one death may be avoided[5], and mortality is halved for those able to reduce from a high dose to a low dose.

<u>Question:</u> As part of the work across JUCD the aim is to reduce the harm of opioid medication, if you feel able to share and you are on medicines for pain, are you hoping to reduce your medication and do you feel attending this group could help you do so?

Although we did ask about medications, it order to maintain trust and honesty within the group, we were very clear that the respondents should only answer if comfortable, as we did

not want them to be concerned that the sole focus of our work was to reduce their medication. Whilst the aim of the pain support groups that we visited is to improve the quality of life for its participants, it was amazing to hear that some participants had successfully reduced or stopped opioid medication, whether on their own or with support from a health professional, because they had the coping strategies they have learned from attending the group. This demonstrates the ability of the programme to help those with Opioid dependence reduce their mortality risk.

One participant reported that they:

"Used to be on Tramadol and Amitriptyline, (I) came off them and was then prescribed Codeine, but this has also been stopped. My Duloxetine has been upped but (my) pain is now bearable due to the group."

Other medications that group participants reported they had been able to reduce or stop included amitriptyline, naproxen, co-codamol and codeine, along with some other neuropathic pain medicines.

The final specific question aimed to gain an insight into who they (as now lived-experience pain support group attenders) felt should attend the group.

Question: Who do you feel could benefit most from attending this group? and why?

There was a split response to this question due to a slight lack of clarity, however we were able to gather information on not only which participants would benefit from attending in their opinion, but also who could attend from a 'guest speaker' perspective.

Feedback regarding which attendees would benefit were consistent across all groups in that family members were suggested so they could understand that it is not just their loved one who is struggling, and to see just how hard life can be for other people with pain. Other suggestions included those struggling with other chronic conditions, such as mental health, as it was felt that these people had similar struggles to people with CNCP.

Suggestions for other 'guest speakers' included pharmacists, physiotherapists, and dieticians/nutritionists so they could provide expert help and advice in required areas (it was reported by the focus groups that some groups did provide these speakers although we did not observe any). GPs and local budget holders were also suggested, to allow them to explain the choices they made that led to the current situation for pain management.

At the end of the semi-structured interview questions, we opened the floor to allow for any other thoughts or comments. There was a resounding response at all groups regarding the 'Post Pain Programme Support' or lack there-of. Some of the groups, particularly those run by the Derby County Football Club Community Scheme, offer more formal post group activities, such as gym memberships, a six-month health and wellbeing programme and access to an allotment. However, others were either non-existent or participant driven. In these instances, it was reported that they had developed their own post-group communities via WhatsApp groups or informal meet ups as they felt there was a risk of hindering their progress:

"I wish there was another course covering the next step and how to keep things going."

The most powerful take away from the feedback we obtained through the questions and observation was regarding the facilitators. Every comment involved nothing but praise for them, and all the effort, compassion and empathy that they show. Many people voiced how instrumental the facilitators had been in getting them to the positive position they were now in to manage their pain. One comment we received was:

"(The) leaders are approachable and happy to discuss things openly. They're friendly and engaging."

Feedback from group facilitators

We also met with the group facilitators, either in person or online, to gain an understanding about how the groups have evolved over time, how they run and what makes them work or not. Initially we asked about recruitment to the groups.

Question: How do you recruit to the group?

The answered mirrored the feedback from participants with the form of recruitment via GPs, social prescribers and other health team members and sessions are for any person struggling with CNCP. Most facilitators said that they were happy to have participants repeat courses and for others, word of mouth supported recruitment along with advertisement in GP practices and local pharmacies.

There were two common answers when exploring the logistics of the groups.

Question: What is it about this group that particularly works and why? Format or logistics? and anything that particularly relates to your population?

Firstly, they expressed the importance of the right choice of venue. Removing the session from the 'GP/medical environment', creating 'welcoming spaces' and ensuring 'easy accessibility' were the most frequent responses. The facilitators shared their insight into how bright and open spaces encouraged attendance and helps participants to transition to the mind-frame of non-medical support. They did not shy away from sharing the challenges either. One group raised the issue that due to their PCN covering a wide geographical area, despite all current attendees being 'local', they were concerned at the inequalities of service provision for those living further away. They did have a plan to alternate the location of future courses to improve access. Additionally, a pilot had run from a local café, but they had found that it was not as private as they had hoped. Additionally, the toilet facilities were not as easily accessible as initially thought, therefore the venue would be changed for future courses.

Secondly, in order for group success, the type of participant was key. Those people that are open to ideas and discussion and happy to chat with others were vital. The facilitators did disclose that those who were closed off to ideas and change did compromise group success. A true example of the quality of the support provision and adaptability by the facilitators is that these participants were then offered one-to-one sessions instead. However, the facilitators did express that managing the expectations of participants in all settings was seen as vital to successful management of pain and was easier to navigate in the more open group of people. One facilitator said:

"(The group will) not be able to take the pain away but help (the members) learn lifestyle techniques on how to manage pain better."

We felt it key to explore how the groups could be improved from those involved in the set up and delivery.

Question: If you could improve the group, what would you do?

Funding was the most prominent topic of conversation, with the highest cost to all the in-person groups being venue hire. Some facilitators expressed that this caused limitations when considering 'guest speakers' or external visits/trips that could be run. It was strongly expressed in all interviews that consistent funding, with longer term commitment, were vital to the sustainability and development of the groups. There were some groups reporting that they had successfully obtained external funding, but this is not replicated across Derbyshire and there has been no commitment to this long-term.

Another facilitator told us:

"The funding is always year to year, so we can't guarantee the long-term sustainability of this support, as it is always down to us to find the funding pots."

There were further issues raised regarding the variety of languages being offered to communities. It was felt that having extra funding, to either train another language speaker or to hire a translator, was seen as crucial to overall success and reducing health inequalities. All the sessions we observed were in English, but Derby and Derbyshire have large communities of Slovak and Czech speakers (among other languages). There was a resounding concern from all groups that the inability to be able to work with this caseload was felt to be frustrating and inequitable whilst there was also acknowledgement to the challenges in addressing this.

There was also a desire for more groups to be run, but this was limited by both facilitator capacity and funding. With the organisation and running of most groups being on top of the facilitator's 'normal' workload, the group leaders felt that there is an overreliance on them. If more time was available, for delivery or organisation, there may be the opportunity for more groups to be run. One group leader informed us:

"(if I had) more time to promote it and had perhaps 2 sessions (it would be better. There would be a 'starters' session, where we intensively go through the ten footsteps, and a different peer support type session people can join if they choose after going through the ten footsteps. Again, not doing this has been down to capacity in our team but also funding to do so…."

The facilitators were invited to share the key points they wanted us to take away from our observation and interviews.

Question: What key things do you want me to leave today knowing about your group?

Facilitators shared an overwhelming sense of pride from delivering the groups, took joy from improving the quality of life for their group members, and were passionate about the need for the groups to not only continue, but develop and grow in size. To aid this, one practitioner left us with this quote about what they felt was needed to continue:

"(we need) demonstration that this helps people improve their quality of life, whilst continuing to experience pain. That there is a reduction in medication use, there are

people who manage to return to employment (paid or voluntary), that there is greater community engagement from those that have participated in our groups. It would help to have someone who can gather and collate this information/evidence and show the comparison between the cost of long-term medication and the financial cost of a participant in a group."

The final aspect we explored with the facilitators was regarding the sustainability of the groups long term.

Question: How can you make sure this group continues for the long term? What would help you to do this?

Funding was a main element to the answers we received, with consistent, sustainable and planned funding being the main ask.

Data was another element some facilitators discussed when talking about demonstrating impact, to allow access to funding that would support sustainability of the programmes. Some of the groups use pain score sheets, some use another outcome measures, and some do not capture any data. One facilitator explained:

"We use the live well with pain score sheets but to get more realistic feedback we get each participant to fill in a blob tree, which in the past we have found helps improve confidence."

Discussion

An NHS digital survey in 2019 found the prevalence of chronic pain in adults to be 34% which increased to 53% in those aged 75 years or older. Chronic pain should be considered a long term condition that has a strong musculoskeletal (MSK) element, with back pain and joint pain in the top three reasons for pain[10]. Chronic pain is pervasive and is seen by all clinicians and all services. It can have a significant impact on a person's mental as well as physical health, and can reduce the person's ability to work.

Our review found that the pain support groups across Derby and Derbyshire had a very positive impact on the participants quality of life, confidence and skills to live well with their pain, and supported a reduction in unnecessary or ineffective pain medicines. Similar results have been found in other studies including the I-WOTCH study [7,8] which was also suggested to offer good value for money for the NHS. This model which has a group consultation style is time efficient for the facilitators who can support multiple people in one session rather than individual support.

Groups were run in different venues across the county but always served the local community. Venue choice is critical with the need for bright, open, accessible spaces that are outside the medical environment, and at convenient locations. Venue hire cost is the main financial outlay for these programmes and acknowledging the value of these venues and identifying a way of ensuring their continued provision is crucial for sustainable provision. It would also allow the facilitators to focus on course provision.

Derby County Community Trust is the charitable arm of Derby County Football Club and their support to provide a number of pain support groups in Derby City is a great example of third sector supporting NHS service provision, and one that has been noticed nationally through the National Medicines Safety Improvement Programme. Continuing to involve third sector or approaching local industries in the area for funding support may be worth exploring as part of a system approach to CNCP.

Apart from one group which was held in the evening, the pain support groups observed as part of this work were held within working hours. The groups were all delivered in English. To improve access we would encourage exploring with potential attendees, especially males, employed people and ethnic minority groups, what their needs are for a programme. We would also recommend exploring options for providing course in other languages. The Enhanced Access scheme, launched in October 2022, encourages PCN flexibility to reflect local needs.

Whilst there are 21 groups currently across Derby and Derbyshire the population as a whole is not covered and we would strongly recommend the scale up and roll-out of this approach as a cost-effective model that supports CNCP management. However, we also acknowledge that one form of non-pharmacological support for chronic pain will not suit all patients and alternative offers such as 1-2-1 support in the community of specialist support from secondary care also need to be offered.

The format, delivery model, and the well-trained and engaging facilitators, works well. As does having the 'ten footsteps' approach and LWWP resources as an underpinning methodology which provides a consistent approach across all groups. The facilitators were all passionate about the programme and were proud of the value it brings to patients. They had all undertaken the LWWP practitioner training to support skills and knowledge development and this course is highly recommended.

Our observations and questioning drew out the importance of the social prescriber and health and well-being coach role, and the benefit of peer learning/support in the success of the pain support groups. This mirrors the results in the I-WOTCH study, where two of their reported themes were 'needing support' and 'the benefits of being in a group'[8]. Social Prescribers were the main facilitators to the groups that we visited as well as the primary referral route, and they created an open and trusting environment were the peer element could thrive. A survey completed by 'Policy Connect' reported that "51% of people say that they can't trust their doctor to deal with chronic pain"[9], the pain support groups provide an effective alternative for care delivery that utilises the skills of the wider practice team and empowers the participant. Retaining the safe environment that encourages sharing with peers, as well as the involvement of lived-experience participants, would be a key recommendation for any group.

There were inconsistencies highlighted in the provision of post course support which was dependent on which PCN the group was associated with. Whilst this is not uncommon in NHS service provision due to commissioning routes and varying PCN priorities, the delivery of effective on-going support was clearly requested by the participants. Current offerings vary from an exceptional suite of support through the Derby County Community Trust supported groups, to repeating the pain support programme, to participant led WhatsApp chats/café meet ups with no facilitation. As a minimum, one model to consider would be to

support a pain café drop-in style approach that is facilitator led to support ‘graduates’ of the course.

The feedback from attendees was overwhelmingly positive but the groups are not necessarily collecting the data that can evidence this impact and support continual improvement. Our recommendation is that measurement should be a key focus for the groups as this will support a business case for continuing the programmes and for scaling up the offer. The LWWP Health and Wellbeing Check data tool would provide an evidenced based method that could be used consistently across groups and HIEM has created a data collection tool to support groups with this approach. At the time of this report, only two of the groups were using the Health and Wellbeing Check tool. However, ultimately collecting useful data is more important than the specific method and if attendees and facilitators prefer a more visual method such as the Jelly Bean Tree this should be encouraged.

Ensuring a local non-pharmacological offer for CNCP is essential to effective patient care and provides clinicians with a viable alternative to prescribing. At the time of writing JUCD is the second highest prescriber of opioids nationally(2). and ensuring effective pain management support is crucial to assisting patients to live well with their pain and reduce the harm from opioids.

The groups use current healthcare team roles to provide maximum benefit to multiple patients at low cost. It is delivered with no risk of harm whilst providing benefits including reduced prescribing, reduced access to other healthcare needs, supports increased independence with the possibility of increasing employment capability, and improves overall quality of life. Therefore, ensuring the sustainability of the groups, and the expansion of support across the population of JUCD should be a priority. The established groups across the county are creating an evidence base for the effectiveness of their groups that we hope this report will add to. It is essential that business planning is undertaken and a commitment for on-going provision is secured at PCN and Place level within JUCD and that CNCP is acknowledged as long term condition, possibly aligning with MSK, that needs support across the system.

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Appendices

Appendix 1: JUCD system approach to improve the management of chronic non-cancer pain

The National Patient Safety Improvement Programmes (SIPs) are a key part of the NHS Patient Safety Strategy. They aim to continually reduce error, harm and death that occur as a result of failures in the system so that the NHS becomes comparable with the safest health care services in the world.

The Medicine Safety Improvement Programme (MedSIP) which is led by NHS England, is one of five primary drivers in the SIP(1). The current focus of the programme is to improve the management of chronic non-cancer pain (CNCP) and reduce harm from opioids. Pain medicines like opioids (e.g. morphine) have minimal evidence for effectiveness in chronic pain but are strongly linked to severe side-effects and should not be routinely prescribed. It is estimated that for every 62 people who stop (or do not start) an opioid, 1 life will be saved (2).

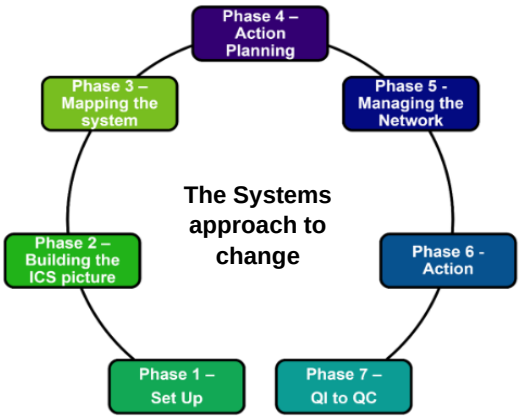

Figure 2: Framework for the systems approach to change

The MedSIP supports Integrated Care Systems (ICSs) to implement a whole systems approach to high-risk opioid prescribing (see Figure 2).

As part of the East Midlands Patient Safety Collaborative, Health Innovation East Midlands (HIEM) has predominantly worked with JUCD, who is one of the highest prescribers of long-term opioids (>3 months) nationally.

The management of CNCP requires personalised care and shared decision making at its core, with patients requiring biopsychosocial support. HIEM have intensively supported JUCD to follow the systems change model (see Figure 2) and this report evaluates the introduction of non-pharmacological support; specifically the development of Pain Support groups across the region.

Appendix 2: Why opioids are not the answer for chronic non-cancer pain

Ongoing CNCP is often termed ‘persistent pain’ and usually described as pain that lasts more than three months that is not related to a cancer diagnosis. Unlike acute pain, CNCP is not related to tissue damage, but people experience persistent pain that can be severe and negatively affect their daily activities and overall quality of life.

CNCP affects one-third of older UK adults(3) and there is not always an obvious cause. It is a long-term condition and can rarely be completely resolved by surgical or medicine interventions. For some people, the pain may reduce over time, and for others there are lifestyle changes that can be made that help them to manage better and live well with CNCP(4). Due to the complexity of managing CNCP, patients may have difficulties accessing effective support which can cause distress.

Opioid medication includes medicines such as Morphine, Fentanyl, Tramadol and Codeine. Whilst opioids have a place in the management of acute pain e.g. post-surgery and cancer-related pain, there is little evidence to support the routine use of opioids in CNCP. The risks and side-effects from opioids are dose related, with doses of 120mg per day of morphine (or equivalent) providing no further benefit but show an increased risk of harm, making them a high-risk medication. National guidance from NICE(4), published in March 2021, recommends that opioids should not be initiated to manage chronic primary pain in people aged 16 years and over, however, a review by Public Health England in 2019 shows that from 2017 to 2018, 5.6 million adults in England received opioid pain medicines (13% of the adult population).

According to national prescribing data from NHS Business Service Authority, in January 2021, over one million people in England were prescribed opioids for more than three months(5).Therefore, if medicines are not the answer to resolving all CNCP, people living with pain need support to help them with non-pharmacological approaches to help them maintain a good quality of life.

Appendix 3: Pain Management Support Group Visits - Questions

Observations from groups

1. Name and location of group? *Number of attendees, gender split*

2. Is it a pain cafe or set number of weeks course

3. If course, what week are you in?

4. Group leaders/facilitators names of those regularly running or organising the group?

5. What is the location like? (easily accessible, city centre based, remote, does it feel safe, etc?)

6. What time does the group run (is it too early or late, does it cross over with school runs or interfere with working age people?)

7. What is the venue like (is it suitable? does it have stairs or a lift, is it light/airy, friendly & welcoming, uplifting or a bit miserable)

8. What demographic of people live in the local area? Is this group reflective of the local population?

9. Does the group run in different languages or languages reflective of the population in the area?

10. What kind of group is it and what is involved in the group? (is it a formal/informal session, do they have people visiting to do talks or help, general activities taking place, movement activities, help and guidance or top tips, sharing experiences)

11. What makes the group good/what is working? (why do people sign up or attend regularly? is there anything we can share with other groups around best practice, what good looks like, top tips, do's and don'ts?)

12. What could be hindering a group/what is not working so well? (are people not signing up or not attending regularly, can we investigate and find out why to help the group)

13. Other

Questions for the Focus group

14. Questions for focus group - What was it about this course that made you sign up and attend today? (how did you hear about?) what did you hope to get out of it?

15. Questions for focus group - What is it about the format, timing or location of this group that particularly works for you or that you would change or improve? (is it a formal/informal session, is it because it is facilitated, do they have people visiting to do talks or help, general activities taking place, movement activities, help and guidance or top tips, sharing experiences)

16. Questions for focus group - Now you have attended this group, what skills have you learnt or what would you like to learn to help you with your pain?)

17. Questions for focus group - How has attending this group made you feel? (empowered more confident? does your family see a change in you?)

18. Questions for focus group - How important is peer support for this group? (do you feel understood or supported?)

19. Questions for focus group - What changes have you made or have happened to your life/lifestyle because of the group?

20. Questions for focus group - As part of the work across JUCD the aim is to reduce the harm of opioid medication, if you feel able to share and you are on medicines for pain, are you hoping to reduce your medication and do you feel attending this group could help you do so?

21. Questions for focus group - Who do you feel could benefit most from attending this group? and why?

22. Other

Questions for group leaders

23. Question for leader - how do you recruit to the group?

24. Question for leader - What is it about this group that particularly works and why? format or logistics? and anything that particularly relates to your population?

25. Question for leader - If you could improve the group, what would you do? (underserved communities, language, number of groups?)

26. Question for leader - What key things do you want me to leave today knowing about your group?

27. Question for leader - how can you make sure this group continues for the long term? What would help you to do this?

28. Other

Appendix 4: Pain Management Support Group Visits – Consent Form

COMMUNICATIONS AND MEDIA CONSENT FORM

I hereby grant the Health Innovation East Midlands (HIEM) the right to use photograph(s), audio recording(s), filming or my testimony or comments (video, audio or written) resulting from interviews or submitted comments (e.g. contained within case studies).

This includes any reproductions or adaptations of the photograph(s)/filming/written comment or testimony. I understand that this could be used for all general purposes concerning HIEM's work including, without limitation, the right to use them in any publicity materials, books, online, newspapers and magazine articles whenever HIEM chooses to do so.

I understand that once this information is published it is in the public domain and could be shared. HIEM has no control over the use of material taken by external agencies, such as newspapers, TV and radio companies either now or in the future. All copyright belongs to the external agency, which retains the right to re-use, broadcast, publish and re-distribute the material worldwide in the future, without seeking further consent.

Under the General Data Protection Data Regulation (GDPR) legislation, I am aware of my right to access on request any photos held by HIEM and receive confirmation on how they are being used. I am also aware of my rights to request any media to be removed by HIEM for future use.
Contact HIEM Communications Team at MS-emahsnadmin@exmail.nottingham.ac.uk

Name……

Name of guardian or child under 16 ……..

Home Address:……..……..……..……..

……..……..……..……

Daytime telephone number:..……Email address:……

Signature of parent or guardian under 16 (if applicable)……...

Date: ……..……

Name of publication/programme: ……..……...

HIEM (NUH) staff member, print: ….……..……

Respondent Sign:…… Date: ……

**Please note this consent form only covers HIEM use, this does not cover the use of third party material – for advice on the use of media of this nature please contact the communications team.*